

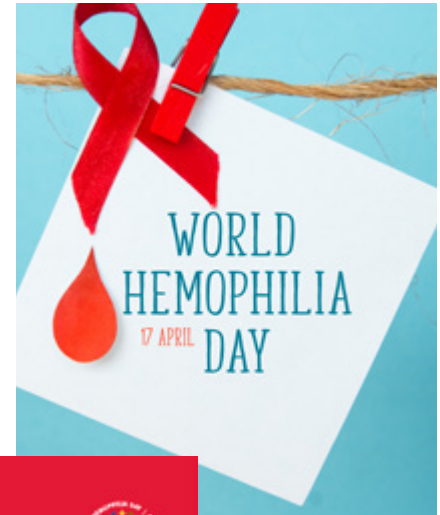
FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

APRIL 17, 2020 IS THE 30TH ANNIVERSARY OF **WORLD HEMOPHILIA DAY!**

The longevity of this celebration is proof of the dedication and tight-knit nature of our community.

The theme of World Hemophilia Day in 2020 is "Get+involved". It's a call to action for everyone to help drive the WFH vision of "Treatment for all" at the community and global level. Whether you are a patient, a family member or caregiver, a corporate partner, a volunteer, or a healthcare provider, we want to encourage you to help increase the awareness of inherited bleeding disorders and the need to make access to adequate care possible everywhere in the world.



2020 ISSUE #1



IN HONOR OF WORLD HEMOPHILIA DAY, JOIN SWOHF FOR A SPECIAL SCREENING OF BOMBARDIER BLOOD.

Thursday, April 16, 2020 at 7:30 P.M. at The Neon (130 E 5th St. Dayton, OH 45402). Tickets available on our website.

BOMBARDIER BLOOD is a powerful documentary about Colorado-based mountaineer Chris Bombardier, who has never let hemophilia stop him from climbing some of the world's tallest mountains. In 2017, Chris partnered with hemophiliac filmmaker Patrick James Lynch to film his journey through Nepal to summit the world's tallest peak, Mount Everest.

- P. 1 Bombardier Blood
- P. 2 Save the Date
- P. 3 Travel Scholarship, SWOHF Board, and Welcome Brittany
- P. 4 Camp Programs
- P. 6 Teens Only: Leading Edge
- P. 8 Bleeding Disorder Awareness Month
- P. 9 OBDC Statehouse Day
- P. 10 Community Connections and Steel Magnolia Award
- P. 11 HTC Corner

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SAVE THE DATE 2020

MARCH

Annual Meeting

Saturday, March 7
Beavercreek Golf Club
Beavercreek, OH

MAY

Evening Out Casino Night

Friday, May 1
Dayton Woman's Club
Dayton, OH

OBDC Statehouse Day

May 19-20
Columbus, OH

JUNE

Family Fest

June 12-14
Higher Ground Retreat Center
West Harrison, IN

JULY

FAMOHIO

July 31-August 2
Columbus, OH

AUGUST

Brad Miller Birdie Busters Golf Outing

Thursday, August 20
Beavercreek Golf Club
Beavercreek, OH

SEPTEMBER

Bleeding Disorders Awareness 5K

Saturday, September 19
Rice Field
Miamisburg, OH

OCTOBER

Fall Outing

Sunday, October 11
Young's Dairy
Yellow Springs, OH

NOVEMBER

Women's Day Together

Saturday, November 14
Golden Lamb
Lebanon, OH

DECEMBER

Teens Only: Leading Edge

December 4-5
Great Wolf Lodge
Mason, OH



SWOHF EVENING OUT: CASINO NIGHT FRIDAY, MAY 1, 2020

BONUS CHIPS FOR TICKETS PURCHASED BY APRIL 1ST!

Tickets are now available for purchase for this event on our website. Cost is \$50 per person.

For more information and to purchase tickets, check our website:

www.swohf.org/programs-events/evening-out



SWOHF TRAVEL SCHOLARSHIP APPLICATIONS AVAILABLE FOR NHF CONFERENCE!

REGISTRATION IS OPEN!

NHF's Bleeding Disorders Conference will be held August 6-8, 2020 in Atlanta, Georgia.

Each year the Southwestern Ohio Hemophilia Foundation budgets to send at least two families to this NHF Conference. SWOHF will pay for transportation and lodging for one affected individual and a second immediate family member to attend. Individuals who receive scholarships agree to be interviewed about their experience for our newsletter or speak at the SWOHF Annual Meeting.

Email kay@swohf.org or check our website swohf.org under Resources to download a Travel Scholarship Form. Forms must be completed and submitted to the SWOHF Office by the deadline indicated for Board review and decision notification. Not all applicants are awarded scholarships.



Welcome to the SWOHF Board, Katie Mullins!

Katie is a senior at Wright State University in their English Literature program. She has von Willenbrand Disease and understands the impact that bleeding disorders can have on a family as her mom and brother also have VWD, and three of her cousins have hemophilia. Katie says, "As I've gotten older, I've decided that I want to work with and give back to the bleeding disorder community. I'm thrilled to have joined the board with SWOHF and I look forward to working more closely with this community!"

2020 SWOHF BOARD OF DIRECTORS:

- Lindsay Carlson, *President*
- Dena Shepard, *Vice President*
- Sandra Hibner, *Interim Treasurer*
- Debra Kremer-Smith, *Secretary*
- Richard Miller
- Katie Mullins
- Eric Shepard (Emeritus)

SWOHF welcomes Brittany Bone as Administrative Assistant! She is working in the SWOHF Office on Mondays and Fridays and will focus on our Social Media (Did you see we are on Instagram?!) as well as SWOHF event planning.

Brittany is an Air Force veteran and has a Bachelor's degree with concentrations in Business and Psychology. She has worked as assistant activities coordinator and a preschool teacher. She has a toddler, Elijah, and loves to go on adventures and make new memories with him.



CAMP REGISTRATION IS OPEN!

SWOHF partners with the Hemophilia Foundation of Michigan to offer camp programs. For children with bleeding disorders, camp is a place where they can learn the valuable skills they need in order to become independent teens and adults. Again in 2020, there are scholarships available for camp so the only cost to the family is a small registration fee!

If you are interested in camp, contact Dayton Children's HTC as applications are completed in their office. You can talk to Cheryl Coffey at 937-641-5877. They will work with SWOHF to provide camper/travel scholarships. *The last day to register is May 22, 2020!*



CAMP BOLD EAGLE

Session 1: Ages 6-9 July 12-16, 2020

Session 2: Ages 10-12 July 18-24, 2020

Teen Camp: Ages 13-17 June 28 - July 4, 2020

At Camp Bold Eagle, kids experience a traditional summer camp environment complete with archery, arts and crafts, canoeing, swimming in a lake, and nature walks. Campers and counselors stay in rustic cabins in the woods and eat meals together in the dining hall.

EAGLE EXPEDITION

Ages 16+ July 28 - August 6, 2020

Eagle Expedition is a weeklong adventure in Northern California featuring activities such as whitewater rafting, rock climbing, sea kayaking and sleeping under the stars.

EAGLE OUTPOST

Ages 14-15 August 9-15, 2020

The Eagle Outpost is a weeklong adventure of traveling by bus throughout Michigan, tent camping in state parks, and cooking over campfires. Activities include swimming, canoeing, tubing, hiking, high and low ropes courses, team building activities, and group discussions. Males and females with bleeding disorders are welcome.

CAMP EAGLE QUEST

Ages 18+ June 6-12, 2020

Eagle Quest is a backpacking excursion on North Manitou Island in Lake Michigan for adults with bleeding disorders. Participants will be responsible for their own food, water, and supplies which they will pack and carry to sustain them for the duration of the camp. This program for adults with bleeding disorders will focus on teamwork, independence, and leadership.

**FOR MORE INFO ABOUT CAMP,
CHECK THE HFM WEBSITE
[HTTPS://HFMICH.ORG/CAMP](https://hfmich.org/camp)**





New HEAD-TO-HEAD Pharmacokinetic (PK) Study Data

See half-life, clearance and other PK data from the crossover study comparing **Jivi**[®] and **Eloctate**[®]

Visit PKStudies.com to find out more.

► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

EMPOWERING TEENS WITH LEADING EDGE!



SWOHF is excited to announce a Teen Program for Friday, December 4 and Saturday, December 5. Our teens will stay overnight on Friday at Great Wolf Lodge (Mason, OH). The resort offers indoor water park fun! On Saturday, SWOHF is partnering with GutMonkey to provide a great program, food and activities, as well as time to enjoy the water park's 13 slides and eight pools, kept warm at 84-degrees year-round. We will have more logistics/details as the event gets closer.

WHAT: Leading Edge Teen Program

WHEN: Friday, Dec. 4 - Saturday, Dec. 5, 2020

WHERE: Great Wolf Lodge (Mason, OH)

WHO: TEENS!!



Thanks to the generous support of Pfizer, SWOHF is thrilled to bring GutMonkey to Ohio! What is a GutMonkey you might ask? Well, it's not a what, but a who. Based in Portland, Oregon, they are an experiential education company with close ties to our hemophilia community.

Leading Edge is an interactive program specifically designed to empower teens with bleeding disorders, helping them develop skills around personal motivation, taking positive risks, setting goals, embracing change when change is difficult, and expanding comfort zones and thus capacity.

Leading Edge has impacted over 25,000 participants from all 50 states for the 14th consecutive year since its inaugural program in 2007! Multi-year study has found that participants have significantly increased their belief in themselves and their abilities at home, school, and when following a treatment plan.

Invitations will be mailed with more information as the event gets closer. PLEASE NOTE: This event is for TEENS ONLY (ages 13-19) with bleeding disorders who are treated at Dayton Children's HTC, Cincinnati Children's HTC or a local hematologist.

SPECIAL THANKS: This program is made possible with funding by Pfizer.



DEDICATION and PERSONAL SUPPORT

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. We are committed to continuing Pfizer's more than 20 years of listening to the hemophilia community and working to meet its needs.



Chris Liddell

Southern OH, MI, KY, IN

"I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community."



PATIENT
AFFAIRS
LIAISONS



248-660-7384 chris.liddell@pfizer.com

MY WORK IS GUIDED BY:

Compassion

Listening to your needs and addressing questions and concerns that you may have

Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, the Coalition for Hemophilia B, and others

HemMobile is a registered trademark of Pfizer Inc.
HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.



REACH OUT

FROM TIME TO TIME INDIVIDUALS FROM THE BLEEDING DISORDERS COMMUNITY ARE INVITED TO SPEAK INTO ISSUES THAT WILL IMPACT HEALTH CARE.

Would you be willing to contact the SWOHF Office if you have recently experienced any issues with:

- Insurance copay accumulator
- Prescription drug nonmedical switching
- Skilled nursing care denial
- Medicaid

This information would benefit our advocacy initiatives.

Call Kay at 937-298-8000 or email kay@swohf.org

FAMOHIO



SAVE THE DATE

July 31st through August 2nd

Marriott Northwest, Dublin, OH

Registration will open in May 2020

Follow us on Facebook at www.facebook.com/Famohio

www.famohio.org

FAMOHioInfo@gmail.com

614-344-1075



DON'T FORGET!

MARCH IS BLEEDING DISORDERS AWARENESS MONTH

WHAT CAN YOU DO?

1. Watch social media for #RedTieCampaign postings. Follow SWOHF on Facebook and Instagram.
2. Change your Facebook Profile Image (check HFA website www.hemophilia.org to download the lower-left image)
3. Share your story with a friend.
4. Wear a red tie! Introduced as the official symbol of the bleeding disorders community in 2016, the red tie reflects the fact that blood—embodied in the color red and the tie—is what binds the community together. Create your own red tie style with a tie, scarf or other favorite red accessory, and share your photos on Facebook and Instagram with #RedTieCampaign
5. Get involved in advocacy efforts, especially at the state level. Join SWOHF for Statehouse Day in May! Just register online and then email kay@swohf.org to let her know you're coming!
6. Volunteer for a SWOHF event or make a donation to SWOHF

I ♥ SOMEONE WITH A BLEEDING DISORDER

Celebrating March as Bleeding Disorders Awareness Month.



OHIO BLEEDING DISORDERS COUNCIL STATEHOUSE DAY



**SAVE THE DATE:
MAY 20, 2020**



Ohio Bleeding Disorders Council Statehouse Day

Each year, the Ohio Bleeding Disorders Council hosts Statehouse Day, where people affected by bleeding disorders educate their state elected officials about issues important to the Ohio bleeding disorders community.

Join us and let your voice be heard.

Please join other bleeding disorder patients, caregivers, healthcare providers and chapter staff, as we walk the halls of the Statehouse in Columbus to educate the legislators on the needs of our community.

Share your personal story to be sure that Ohio continues to provide access to comprehensive care for bleeding disorder patients.



Dinner and training will be provided Tuesday, May 19, 2020.

Hotel rooms and travel stipends available upon request with priority given to new attendees and those driving more than 60 miles.

Registration will open in March. Please visit www.ohiobdc.org for registration information.

For more information, contact obdcsvp@gmail.com





COMMUNITY CONNECTIONS

On December 4, 17 individuals gathered at Coco's Bistro to enjoy dinner together and learn about hemophilia treatment options. Thanks to Carol DeMatteis from Sanofi Genzyme for her presentation and sharing support resources for those individuals with hemophilia.

Mark your calendar for March 18, 2020, and watch for invitations in the mail with more details for our next educational dinner provided by Sanofi Genzyme.

SWOHF MEMBER JULIE SAMPSON: 2019 STEEL MAGNOLIA AWARD RECIPIENT



Julie Sampson has been selected as the West Chester area's 2019 Annual Steel Magnolia Award honoree. The award honors women who have faced adversity and shown strength, courage, compassion, along with positively impacting their community. The program is administered by the Middletown Community Foundation and funded by the AK Steel Foundation.

Nominations by essay were solicited from the public in each of the 13 communities where AK Steel operates a facility. Julie was nominated by her husband, Matt, who said, "On top of her work as a caregiver, she donates her time and resources and reaches out to others."

Along with the award, Julie was able to designate the charity of her choice to receive a \$2,500 contribution. SWOHF recently received this donation, in honor of Julie, and would like to thank her, AK Steel and the Middletown Community Foundation for their generosity.



HTC CORNER

MEET BETH LINEGANG!

In October 2019, Dayton Children's HTC hired Beth Linegang (pictured right) as resource nurse. She graduated from the University of Dayton and remains a huge Dayton Flyers fan. GO FLYERS! She got her Associate's and Bachelor's degrees from Miami University of Ohio. She also received a Master's degree in Global Public Health Nursing from Cedarville University which focuses on health promotion, prevention, and access to care. She has worked at Dayton Children's as a nurse for the last 16 years and also spent 10 years as a Home Care nurse which is where she learned about hemophilia and other bleeding disorders through providing home infusions to many patients. The last six years prior to joining the HTC, she was the Infection Preventionist.

Born and raised in North Central Ohio, Beth loves the snow and also enjoys vacations at the beach. She has three children, one who has von Willebrand's and she understands how scary and confusing these diagnoses can be for parents. She's excited to get back to providing patient care and to be a part of the amazing Dayton Children's HTC team.

MEET BRITTANY JACKSON!

Brittany (pictured left) began her role as Medical Social Worker in the Dayton Children's HTC in January 2020. She graduated from Wright State University in 2013 with a Bachelor's degree in Rehabilitation Services and obtained her Master's degree in Social Work in 2017. Her

career began in 2014 working with Samaritan Behavioral Health Crisis Care. In 2017, she was employed by Montgomery County Juvenile Probation working specifically with their Mental Health program.

Born and raised in Dayton, Ohio, Brittany loves helping others and enjoys giving. Brittany is committed to being a lifelong learner and is eager to learn more about how social work can best serve the Hemophilia population. She's excited to begin Medical Social Work and be a part of the amazing Dayton Children's HTC.



The material provided in Factor Notes is for your general information only. SWOHF does not give medical advice or engage in the practice of medicine. SWOHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

MISSION STATEMENT

SWOHF helps improve the quality of life for those affected by hemophilia, von Willebrand disease, and other bleeding disorders by providing support education, networking, advocacy, and services to individuals, their families and the community.

EXECUTIVE DIRECTOR

Kay Clark

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